

These days I pay attention to stroke literature. No big surprise. We all tend to pay attention to the things that are up close and personal. Most stroke literature talks about preventing strokes. Prevention is good and important work. Many conditions exacerbate the risk of stroke and can and should be controlled. Nobody who thinks about it wants to encourage anyone to have a stroke. But the point is that strokes happen regardless, and there's so much more we can learn about what to do after a stroke. And we can learn what this experience — and what any powerful, life-changing experience — has to teach us.

On May 3, 2002, I woke up and got out of bed to go to the bathroom. It was morning, around seven o'clock, on a lovely warm day. I'd gone to bed early the night before and was well rested, eager to get back to work on my lifelong dream. When I stood up, I noticed that I felt shaky. I walked the very short distance to the bathroom, noticing the slightly odd way I was walking. I sat down on the toilet to pee; I knew I was urinating because I could hear myself, but I couldn't feel it. "How strange," I thought.

I have a tendency to experience low blood sugar, so my next thought was "This is the worst case of low blood sugar I've ever had." I headed to the kitchen to get a piece of fruit as a quick way to raise my sugar level. Our house is small. The kitchen shares a wall with the bathroom and the bedroom, and its far side opens into the living room. I came out the bathroom door, turned left, and reached for a piece of fruit. The nearest was an orange, which required that I either peel it or cut it. Cutting seemed easier, so I picked up a knife.

I looked down and wondered at how much trouble I was having directing my hands. “Really, really low blood sugar,” I thought.

Then the phone rang across the room. The phone sits on a table beside a blue couch by the windows with the long view over the bay. I walked over, answered the phone, sat down, and began to talk. Something was funny with my speech. I was having trouble forming words. The person on the other end, my husband’s daughter, noticed immediately that my speech was slurred. “Hang up and call 911,” she said. She didn’t say, “You might have had a stroke.” I had no clue what was happening. I was still operating on the low blood sugar premise. I listened politely, but I didn’t think it was a big deal, so I thanked her and hung up the phone. To humor her, I decided to dial the twenty-four-hour on-call nurse at my health plan, Kaiser Permanente. Of course the on-call nurse knew what might be going on. She immediately told me to call 911.

Feeling quite foolish, I woke my beloved husband, Bob, and called 911. We lived on a mountain and knew the paramedics at the fire station up the road from various disaster-planning activities in our neighborhood. The station was only three minutes from our house. In a very short while, paramedics I knew came up on the porch and in the door. They proceeded to start the drill I’d learned in my first-responder training, asking me the usual questions — starting with “What’s your name? What’s today’s date? Where are you?” — all of which I answered easily, feeling more and more foolish. Then they called the ambulance to take me to the hospital.

Paramedics are wonderful. If I ran the world, paramedics would be paid more than the people who play professional sports.

As we waited for the ambulance, I was still thinking that this response was way, way over the top, and I was both scared and embarrassed. The ambulance came, bringing more paramedics with it. The new ones put me in a lift chair, carried me down the steps, and loaded me into the waiting ambulance. They wouldn't let me sit up. They insisted I lie down, and they took my blood pressure. One of them sat beside me the entire trip. I struck up a conversation with this paramedic, who like all the rest was a lovely person — friendly, warm, and professional. I thought that I would rather talk to him than think about how silly I felt, lying there in an ambulance with my beloved husband following behind in his car.

At the emergency room I was taken in right away and sent for a CAT scan. A little while later the doctor came in and said, "You have bleeding on your brain stem. You might die. But I think you'll be all right." I was fifty-five and fit, right? I didn't think I was going to die. I still didn't know that I'd had a stroke. All I concentrated on were the last words he'd said: "... you'll be all right." "Fine," I thought. "I'll be all right. Let's get out of here."

Fortunately, the doctor was wiser than I and insisted that I be admitted to the neurological intensive-care hospital an hour south of my house. This required another ambulance ride and another long stretch of following behind for my husband in his car.

At the new hospital, the neurologist told me that he would

have sent me home. Luckily for me, the emergency-room doctor at the first hospital had other ideas. After a long wait in the emergency room at this second hospital, I was admitted, placed in the neurological intensive-care ward, and given treatment to attempt to reduce the swelling in my brain. Brains don't like blood loose in the wrong place. The brain sees blood outside the veins, arteries, and capillaries as poison. Loose blood kills brain tissue, and the rest swells up in response to the injury. It's a good thing that I was in the hospital, because sometime after midnight, on May 4, I had another bleed, with the potential for ever more swelling and escalating damage.

Sometimes when people have hemorrhagic strokes, neurologists perform brain surgery to stop the bleeding. They don't like to do this with the brain stem. The brain stem is the old part of the brain. It's little. It's compact. It controls really important things like breathing and your heartbeat. Cutting it open can do more harm than good. Serious swelling and pressure on the part that regulates your heart or your lungs can make you dead. We could only pray that the bleeding was stopped and wouldn't start again.

Only enough blood to cover an area of roughly 2.7 centimeters in diameter got loose in my brain. That's not much, not much at all. But that little bit of blood in the wrong place, in that highly delicate brain stem, caused the following problems: My left arm was completely paralyzed. Most of my left leg was paralyzed. My trunk muscles wouldn't respond. I couldn't sit up. My right arm and leg responded to my thoughts of moving them, but they were wildly uncoordinated and wandered

all over the place. My swallowing reflex was gone. I had to have a feeding tube inserted up my nose and down my throat. My speech was heavily slurred, and I had very little breath with which to speak. I was pretty hard to understand. My eyes wouldn't focus. My ability to control my emotional expression was shot. I either looked as if I were devoid of feeling or I laughed or cried uncontrollably — often both at once. I lost control of my bladder and my bowels, so I had to wear diapers, which was better than what happened later, when my ability to urinate on my own shut down for ten days and I had to be catheterized every six hours.

If you have never had a brain injury or a stroke (and I hope you never have and never will), you'll find that it's virtually impossible to imagine the depth of the injury and the overwhelming fatigue that accompanies it. You can see the obvious disabilities in people who've had strokes or other brain injuries. But what you can't see is the extraordinary effort it takes to do the smallest thing. What you can't see is the way the body responds to the attack on such a fundamental organ. The power of that fatigue is unlike anything I'd ever experienced; there's nothing even close.

So many problems were created from a little bit of blood in the wrong place. I'd received a real-world lesson in just how fragile bodies are. And now I was in the hospital, profoundly injured and disabled, and the lessons this experience would teach me began. I couldn't see them as lessons at first. I was struggling to stay alive. But nonetheless I was beginning to discover the power of transformation.

I was beginning to learn that it's not what happens to us

that matters, not even something as bad as a brain-stem stroke. What matters is how we deal with what happens to us. How we work with what is — whatever that might be — makes all the difference.

The rest of this book is about what I learned and how I apply these lessons to my whole life, not just to my recovery, which, by the way, has been remarkable. I'm aware of my continuing limitations, but most folks have no idea I had two strokes unless I tell them.